Wendy Votroubek

Aaron Tabacco

Third Edition

# Pediatric Home Care for Nurses

A Family-Centered Approach

# **Contents**

HOME CARE

Foreword xii	
Contributors	xv
SECTION I: TH	ECORETICAL AND CONCEPTUAL COMPONENTS OF PEDIATRIC
Chapter 1	Theoretical Foundations for the Nursing of Families 1 Introduction 1 Family Healthcare Nursing Practice 2 Approaches to Family Nursing Practice 2 Obstacles to Family Nursing Practice 3 Why Teach Nurses Family Nursing? 4 What Is the Family? 4 Family Function, Structure, and Process 4 Theoretical Perspectives 8 Summary 15
Chapter 2	Ethics in Pediatric Home Care 17 Introduction 17 Overview of Theories and Approaches 18 Ethical Principles 20 Responsibilities and Roles 22 Summary 33
Chapter 3	Financing of Pediatric Home Care 37 Introduction 37 Pediatric Home Care: Basic Definitions 38 Costs of Home Care 39 Funding Sources 39 Tricare 46 Navigating the System 47 Children with Special Healthcare Needs 52 Financial Considerations 55 Summary 55
Chapter 4	Nursing Assessment of the Family 59 Introduction 59 Child and Family Concepts 60 Factors that Affect the Assessment Process 64 Developing Nursing Practice: Family Assessment 69 Summary 78
SECTION II: N	Vursing Care of Children and Families—Diagnoses
Chapter 5	Care of the High-Risk/Medically Fragile Infant 81 Links 81 Books 82 Introduction 82

Acknowledgments xi

Chapter 6

Chapter 7

Chapter 8

Theoretical Concepts/Models 83 History of Neonatal Intensive Care 83 Discharge of the High-Risk Infant 84 System or Organ Development and Functional Overview, Assessment 85 Primary Care of the High-Risk Infant 89 Nursing Diagnoses 89 Diagnosis-Specific Information 91 Parent as Caregiver—Education Needs 99
Care of the Child with Altered Neurophysiological Function 107 Introduction 107 Conceptual Framework 108 Historical Development 108 Overview of System and Function 110 Nursing Diagnosis 110 Cerebral Palsy 110 Spina Bifida 117 Hydrocephalus 132 Spinal Cord Injury 134 Traumatic Brain Injury 140 Seizures 143 Summary 152
Care of the Child with Altered Respiratory Function 157 Introduction 158 Theoretical Concepts/Models 159 Historical Development 160 Diagnostic Tests Related to Children with Respiratory Dysfunction 161 Functional Overview for the Oxygen-, Tracheostomy-, and Ventilator-Dependent Child 164 Nursing Diagnosis 167 Nursing Care 167 Additional Nursing Issues for Oxygen-, Tracheostomy-, or Ventilator-Dependent Children 177 Diagnoses-Specific Discussions 178 Skilled Nursing Care in the Home 182 Functional Overview for the Child with Cystic Fibrosis 183 Nursing Diagnosis 187 Nursing Care 187 Additional Nursing Concerns for the Child with Cystic Fibrosis 196 Functional Overview for the Child with Asthma 196 Nursing Diagnosis 198
Nursing Care 200 Additional Nursing Concerns: Asthma Medications 208 Summary 210
Care of the Child with Altered Cardiac Function Community Resources for Families 217 Introduction 218 Overview of Cardiac Anatomy and Physiology 219 Nursing Diagnosis 220 Diagnostic Methods 220 Heart Disease 220 Congenital Heart Defects 224 Acquired Cardiac Disorders 226

	Cardiomyopathy and Heart Transplant 231 Cardiac Surgery 232 Summary 237	
Chapt <b>ei</b> 9	Enteral Devices and Intestinal Diversions for the Child with Altered Gastrointestinal Function 245 Enteral Feeding Devices 245 Nursing Diagnosis 246 Enteral Feeding Tubes 247 Nursing Care of Enteral Feeding Tubes 252 Nursing Care of the Child with Total Parenteral Nutrition 261 Intestinal Diversions 263 Nursing Care Issues of Intestinal Diversions 268 Elimination Strategies for Patients with Altered Colon Function 270 Summary 274	
Chapter 10	Care of the Child with Altered Gastrointestinal Function 278 Introduction 278 Family Theory 278 Common Tests 278 Nursing Diagnosis 278 Constipation 278 Celiac Disease 283 Gastroesophageal Reflux 290 Short Bowel Syndrome 298 Summary 305	
Chapter 11	Care of the Child with Altered Endocrine Function 309  Parent Resources 309  Introduction 310  Conceptual Model: Coping with and Adapting to a Chronic Illness 311  History of Diabetes Care 312  Pathophysiology of Diabetes Mellitus 313  Nursing Diagnoses and Care Plans for the Child with Diabetes Mellitus at Home 3  Diabetes-Specific Information 319  Age-Dependent Diabetes Self-Management 325  Diabetes Care at School 329  Care of the Family 330  Summary 331	317
Chapter 12	Care of the Child with Altered Renal Function 333  Parent Resources 333  Introduction 333  Historical Development 334  Theoretical Concepts 334  Systemic Development 334  Nursing Diagnosis 335  Nursing Care of Child with Hypertension and Acute and Chronic Renal Failure  Nursing Care of the Child with Dialysis and Kidney Transplant 340  Summary 349	335
Chapter 13	Care of the Child with Altered Liver Function 353 Introduction 354 Conceptual Framework 354 Historic Overview and Current Research 355 The Liver 356	

	Common Laboratory Tests in Liver Disease 356 Nursing Diagnosis 361 Cholestatic Liver Diseases 361 Genetic Disorders 366 Inborn Errors of Metabolism 371 Autoimmune Liver Disorders 378 Tumors 383 Hepatitis 385 Caring for the Family 395 Summary 395
Chapter 14	Home Care of the Child with Altered Hematopoietic Function Introduction 402 Theoretical Concepts and Models 402 Historical Development 402 Overview of the Hematopoietic System 403 Nursing 403 Common Pediatric Hematological Disorders 405 Common Pediatric Coagulopathic Disorders 415 Common Immunodeficiency Disorders 419 Home Care of the Child with Altered Hematopoietic Function 423
Chapter 15	Care of the Child with Cancer 427 Introduction 428 Historical Development 428 Nursing Diagnosis 429 Diagnosis-Specific Discussions 429 Diagnosis 429 Treatemnt Modalities 430 Development, Growth, and Nutrition 446 Symptom Management 448 Other Symptoms 457 Safe Handling of Chemotherapy and Biotherapy 458 Discharge of the Pediatric Oncology Patient 459 Care of the Patient at the End of Life 459 Models of Care and Care of the Family 462
Chapter 16	Care of the Child Post Organ Transplant 471 Quick Links 471 Books 472 Introduction 472 Conceptual Framework 472 Nursing Diagnosis 473 Transplant Process Components 473
SECTION III:	NURSING CARE OF CHILDREN AND FAMILIES - DEVELOPING PRACTICE
Chapter 17	Pediatric Pharmacology 495 Introduction 495 Developmental Pharmacology 495 Pediatric Drug Administration 499 Safety Concerns in the Home 504

### Chapter 18 Pediatric Pain Assessment and Management 509 Introduction - 509

Over-the-Counter Medications 504

Summary 507

ix

Pain Ana	itomy,	Phy	ysiolog	y, an	d Theo	ry	510	
General '	Tenets	of:	Home	Pain	Manag	eme	nt	517
	_		_		<b>.</b> .			_

### Chapter 19 Life Span and Developmental Transitions 529

Introduction 529

History, Literature, Practice 531

Transition Issues 531

### International Views: Community-Based Palliative Nursing Care in the Chapter 20 United Kingdom 551

Introduction 552

Exploring Issues in End-of-Life Care 553

Palliative Care for Children and Young People, and Their Families 555

Models of Team Working 557

Key Worker Role 557

Facilitation of Trust Between the Nursing Team, and the Child/Young Person and

His or Her Family 558

Pain 563 Summary 564

### Family-Centered Care Coordination 567 Chapter 21

Introduction 567

Understanding Care Coordination 568 Implementing Care Coordination 573 Technology and Communications 578 Cultural Competency 578

Barriers to Effective Care Coordination 579

Summary 580

### The Nurse Role in Parent Education 583 Chapter 22

Introduction 584

Historical Development 584 Developing Practice Expertise 585

The Role of the Nurse in Parent Education 589

Summary 590

### Parenting the Special Needs Child 593 Chapter 23

Incidence of Handicapping Conditions 594

Parental Response to the Diagnosis of a Disabling Condition 594

Crisis Theory 596

The Art of Parenting 600

Common Themes of Uncommon Parents 603

Summary 608

# SECTION IV: NURSING CARE OF CHILDREN AND FAMILIES-THE INTERDISCIPLINARY TEAM

### The Role of Physical Therapy in Pediatric Care 611 Chapter 24

Introduction and Background 612 Physical Therapist in Pediatrics 614

Important Concepts in Physical Therapy Practice 618

Summary 627

### The Role of Occupational Therapy in Pediatric Care 629 Chapter 25

Introduction 630

Occupational Therapy in Pediatrics 630

Credentials 631

Theories of Practice in Occupational Therapy 631

Assessment 634

Impact on Functional Performance 635 Intervention Models 636

# Chapter 26 The Role of Speech-Language Pathology in Pediatric Care 641

Introduction 642

The Profession of Speech-Language Pathology 642
Where Speech-Language Pathologists Work 642
Speech-Language Pathology Scope of Practice 643
Causes of Communication Disorders 647
Erecuency of Communication Disorders 648

Frequency of Communication Disorders 648 Activities of a Speech-Language Pathologist 649 When Delays Require Professional Attention 651

# Appendix: Speech-Language-Hearing Development in Preschoolers: A Guide to Typical Communication Development from Birth through Five Years 653

Communication 653

# Chapter 27 The Role of Nutrition Therapy in Pediatric Care 657

Introduction 658

Historical Development of Nutrition and Dietetics 258

Education and Practice of the Dietitian 658 The Dietitian and Care of the Child 659 Access to Care 671

Interplay of the Nurse and Dietitian 676

# Chapter 28 The Role of Special Educators and Special Education Law in Pediatric Care 679

Introduction 679

Role and Training of Special Educators 680

Federal Laws Relating to the Education of Children and Youth with Disabilities 682 School Advocacy and Special Education 691

# Chapter 29 Social Work 695

Historical Background and Role of Social Worker 695 Education and Scope of Social Work Practice 696 When Social Work Services Are Indicated 696 Common Methods and Types of Intervention 697 Reimbursement 704 Interface Between the Nurse and Social Worker 705

# Chapter 30 Family Voices 709

Tell Me I'm Strong and Brave 709
Matthew the Human 710
Please Hear Me 711
I Want Someone Else to Be the Mom 711
I Wish I Had a Roadmap 712
Big News, Big Big News 712
My Special Family 713
Our Son, Our Hero 714
Please, Please Listen 714
Child First, Diagnosis Second 715
The Kindness of Strangers Is Immeasurable 715
Top 20 Words of Wisdom from Families 716

## Index 719